



Perspectives of patients and family members regarding psychological support using intensive care diaries: An exploratory mixed methods study [☆]



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ABSTRACT

Purpose: Diaries summarizing intensive care are routine practice in some countries, although evidence to support diary use is limited. The purpose of this study was to identify whether distress post-intensive care influences patients' and relatives' choice as to whether they would like to receive a diary and what information delivery method is preferred.

Materials and methods: Intensive care patients admitted for at least 3 days and their relatives participated in an exploratory mixed methods study. Interviews were conducted 3 to 5 months after discharge. Psychological distress was assessed using Kessler-10 and Posttraumatic Stress Disorder Symptom Checklist — 5. Perceptions of benefit of diaries were assessed using a 4-point Likert scale. Differences were examined using Fisher exact test ($P < .05$).

Results: Fifty-seven patients and 22 relatives consented to participation, with 22 patients and 22 relatives interviewed before data saturation. Psychological distress was evident in 25 (47%) patients and 5 (23%) relatives. Participants' psychological health was similar for those who perceived diaries as beneficial, and those who did not. Themes included memory, process, and impact, although opinions were diverse.

Conclusions: Patient and relative preferences of receiving a diary are not related to psychological distress. Diverse opinions around common themes suggest the need for a range of interventions to aid psychological recovery.

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1. Introduction

Physical and emotional recovery from critical illness can be complex and prolonged. Survivors of critical illness and their family members frequently experience significant psychological distress, including anxiety, depression, and posttraumatic stress that may continue for some time after intensive care unit (ICU) discharge [1–3].

After ICU admission, many patients struggle to remember events that led to, and occurred during, their ICU stay [4]. Patients are often left with delusional memories of their ICU experience, caused by a milieu of stress, pain, illness, and medications [4]. During a patient's ICU stay, family members need to comprehend and remember a new language of medical terminology, during a time when they are already under stress and experiencing new events and activities for the first time. Family members consistently report a need for improved communication with the interdisciplinary team during ICU admission [5,6].

Intensive care diaries have been proposed to provide a written and/or pictorial account of patients' ICU experience, to improve

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communication and promote psychological recovery for patients and family members [7–10]. Although ICU diaries have been incorporated into routine care in many European countries, the diary format, content, timing, and method of delivery vary considerably [9]. The effectiveness of intensive care diaries to improve psychological recovery for patients and carers has not been established [10], with only 2 randomized controlled trials [7,11], 1 case-control [12], and 1 meta-analysis [10] undertaken. However, prevalent reports of patient and clinician acceptability and satisfaction have overshadowed the lack of information regarding their safety and effectiveness [9].

Published studies to date have provided preliminary evidence that intensive care diaries likely provide benefit to some patients [7,11], although rates of patient inclusion in some studies have been low [9]. Furthermore, patients recovering from ICU are a diverse and vulnerable population and psychological interventions can have a powerful positive, negative, or mixed impact on a patient's recovery. Giving patients an ICU diary as a tool to promote recovery assumes that patients want to know about what happened while they were in ICU, and that this knowledge is beneficial [7]. However, the limited research suggests that only 50% of patients wanted to know more about their ICU experience [13,14]. In addition, accurate memory has not been consistently demonstrated to improve recovery [15,16]. Providing large quantities of variable information to a patient already suffering from significant distress, without appropriate support, may inhibit recovery [17].

Intensive care unit diaries need to be developed in a manner that ensures safety, and be targeted at those who are most likely to benefit [9]. This study of ICU survivors and their families, from 1 Australian ICU, sought to elicit views and preferences of diaries, by identifying the following: (a) which patients and family members would wish to receive a diary; (b) whether distress post-ICU influenced patient and family members choice regarding receipt of a diary; (c) what content should a diary include; and (d) practical considerations regarding receipt of information, either in a diary or alternative format.

2. Materials and methods

2.1. Study design

An exploratory mixed methods study was undertaken in a large tertiary, metropolitan hospital in Brisbane, Australia. The study was approved by the Metro South Health (HREC/13/PAH/694), Griffith University (NRS/13/14/HREC), and University of Queensland (2014000520) Human Research Ethics Committees.

2.2. Participants

Participants were recruited in 2 groups—ICU patients and family members. Patients with an ICU length of stay at least 3 days and who were expected to survive to hospital discharge were eligible for inclusion in the study, whereas family members were required to be the nominated family member of patients who met the inclusion criteria. Both patients and family members were aged 18 years or older, able to speak and understand English, and accessible for interview (in person or by telephone).

2.3. Phase 1: psychological measures

Psychological distress was measured using Kessler-10 Psychological Distress Scale (K10) [18] and the PostTraumatic Stress Disorder Symptom Checklist – Civilian V5 (PCL5) [19]. The K10 is a 10-item self-report cumulative scale calculated by the frequency of distress symptoms; with a total score range 1 to 50, with higher scores indicating greater distress. The symptoms measured include depressed mood, motor agitation, fatigue, worthless guilt, and anxiety [18]. The PCL5 is a 20-item self-report measure that assesses the symptoms of posttraumatic stress disorder, as described in the Diagnostic and Statistical

Manual of Mental Disorder, Fifth Edition [20]. To be categorized as symptomatic, symptoms must be evident across the clusters of intrusion, avoidance, negative alterations in cognitions, and mood and alterations in arousal and reactivity [20]. Participants with a K10 score greater or equal to 20 (indicating mild to severe distress [18]) and/or a PCL5 meeting the criteria of being “symptomatic” were categorized as “distressed.”

Participants also indicated if they considered an ICU diary would have been helpful in their recovery using a 4-point Likert-type scale (1 = not interested, 2 = somewhat not interested, 3 = interested, 4 = very interested). For categorical analysis, categories 1 and 2 were grouped as “not interested” and categories 3 and 4 as “interested.”

2.4. Phase 2: interviews

Exploratory interviews were undertaken to gain a rich understanding of the ICU patients and family member views of the potential benefits of ICU diaries and thoughts regarding content, contribution, and timing. Questions that guided the interview included the following:

- Would you have liked to receive a diary summarizing your/your family members' ICU stay?
- If you were to receive a diary, what content would you like to have incorporated into the diary?
- If you were to receive a diary, at what time point would you like to receive this diary?
- Would you like to have photos of yourself/your family member in ICU included in the diary?
- Who would you like to write in your diary? (eg, family members, ICU nurses, any ICU staff)
- Do you have any other thoughts about the potential value or content of ICU diaries for patients?
- Is there an alternative format that you would have liked to have received information about your/ your family members' ICU stay?

2.5. Data collection

Patients and family members were approached for informed consent either upon awakening in ICU or after transfer to a ward, and was reconfirmed at the beginning of each follow-up contact. Participants were then followed up 3 to 5 months after ICU discharge. Questionnaires were sent to participants via electronic or conventional mail, and then followed-up via telephone. The order of content of follow-up was standardized with information regarding the general format and content of a potential ICU diary initially provided. Thereafter, participants reported their previously completed self-report questionnaires relating to psychological distress over the past 30 days (ie, K10 and PCL5); finally, diary preferences were recorded. Interviews were conducted in person, or by phone, with both options available to increase ease of participating and reduce discrimination against potential participants who lived long distances from the hospital. Interviews were conducted as soon as possible after the completion of the psychological distress questionnaires and lasted for an average of 11 minutes (range, 3–28 minutes). A second phone call was scheduled if the participant requested completing the interview in stages rather than in a single contact.

2.6. Data analysis

Demographic and clinical characteristics of the study population were summarized using the appropriate descriptive statistics. Psychological distress symptoms were described based on categories identified by the scale developers [18,19]. A significant relationship between level of psychological compromise and patient desire for an ICU diary was determined using Fisher's exact test ($P < .05$). Missing data were described

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